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Expanding Public Health Surveillance for People with Intellectual and Developmental Disabilities in the United States

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Background

Surveillance, as used in public health, refers to tracking incidence and prevalence of target populations as well as identifying characteristics that can influence or contribute to their health. A frequently cited figure for intellectual disabilities and developmental disabilities (ID/DD) prevalence in adults in the U.S. suggests approximately 4.6 million Americans live with these conditions, or about 1.5% of the adult population (Larson, Lakin, Anderson, Kwak, Lee, & Anderson, 2000; Larson, Lakin, Anderson, Kwak, Lee, & Anderson, 2001; Fujiura & Taylor, 2003). There are two primary reasons why this figure continues to be cited approximately 15 years after its initial publication. The first is that it uses data from a supplement to a well-respected, national health survey of people in the American population conducted in two phases during 1994–1995. This survey provided extensive health data on the disability population, but has not been administered since. Absent a more recent update, the Disability Supplement to the National Health Interview Survey (CDC, 2015) continues to be used in spite of health and demographic changes in our general population since then that may call into question the accuracy of these prevalence numbers today. The second reason relates to the structural difficulties inherent in population-based surveillance for people with ID/DD using other approaches. These include a lack of a widely agreed upon operational definition, and challenges in administering surveys for ID/DD populations relating to communication, overcoming stigmatization, maintaining confidentiality, and assuring accurate proxy reporting.

In spite of these structural difficulties that may have prevented broad surveillance of ID/DD, smaller studies have documented the health status and health needs of people with ID/DD. As a group, adults with an ID experience substantially poorer health outcomes than adults without an ID (Anderson, Humphries, McDermott, Marks, Sisirak & Larson, 2013; Krahn &

Disclaimer: The findings and conclusions in this manuscript are those of the author(s) and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

Fox 2013; Krahn, Fox, Campbell, Ramon, & Jesien., 2010). Compared with peers of a similar age, they are more likely to live with complex health conditions (Krahn, Hammond, & Turner A, 2006), have poorly managed chronic conditions such as epilepsy, hypertension, and obesity (e.g., Bowley & Kerr, 2000; McDermott et al., 2005; Janicki et al, 2002; Balogh, Brownell, Ouellette-Kuntz, & Colantonio, 2010), have limited access to appropriate health care and health promotion programs (Hayden, Kim, & DePaepe, 2005), receive breast cancer and other health screenings at lower rates than those among the general population (Parish & Saville, 2003), have undetected vision and hearing loss (Woodhouse, Adler, & Duignan, 2004), and have mental health problems and potential overuse of psychotropic medications (Emerson, 2011; Bartlo & Klein 2011; Holden & Gitlesen, 2004; Lewis, Leake, King, & Lindemann, 2002).

With this expanding body of evidence pointing to inadequate health management and care, the need for ongoing and more sustainable health surveillance for ID/DD populations in the U.S. has become clearer. But even as the need for this surveillance has become apparent, so have its technical challenges. Three primary issues on data collection efforts for ID/DD populations are:

1. *Representativeness* – the difficulty of surveillance approaches to include a representative sample of adults with ID/DD;
2. *Validity* – the lack of appropriate validated measures to identify people with ID/DD; and
3. *Methodology* – methodologies that prevent people with ID/DD from participating.

Each of these issues can be found when examining more closely two current health assessment tools that capture data for ID/DD.

Extant Health Assessment Tools

National Core Indicators (NCI; HSRI, NASDDDS, 2015)—Begun as a state-level quality assurance tool, NCI collects indicator information from a sample of people receiving DD services from state agencies. From an initial 13 participating states in 1997, the project has grown to include 42 U.S. states (including DC) and 22 sub-state regions. It serves as a multi-state database on outcomes for people who are receiving long term services and has been used to explore programmatic and demographic issues affecting people with ID and their families. Reports examine the use of psychotropic medications, health behaviors, access to primary health care, and document significant disparities in health and health care utilization compared to the general population (Havercamp & Scott, 2015). Its primary limitations are that its sample is limited to people receiving services, and questions persist about true randomization of sample and adequate standardization in data collection. Proxy reporting is allowed for a portion of the data collection to ensure people who are not able to self-report are included in the dataset, but these proxy responses are not collected for subjective measures of quality of life as these have not been shown to be valid or reliable (Andresen, Vahle, & Lollar, 2001).

Special Olympics Healthy Athletes. (Special Olympics International)—Special Olympics has been collecting health screening data on its participating athletes for more than two decades, and its findings were the impetus for the 2002 Surgeon General’s report on health needs of people with ID (USPHS, 2001). Numerous studies have reported on Healthy Athletes screening data for oral health, obesity, vision, hearing, nutrition and general fitness (e.g., Horowitz, Kerker, Ownes, & Zigler, 2000; Special Olympics, 2009; Foley, Lloyd & Temple, 2014). Limitations of this data set for population health surveillance are its limitation to Special Olympics athletes who volunteer to participate, and the lack of an individual identifier to reduce redundancies and allow longitudinal monitoring over successive screenings.

CDC activities associated with expanding surveillance for ID/DD

Developing the plan for health surveillance for ID/DD

The Centers for Disease Control and Prevention’s (CDC) National Center on Birth Defects and Developmental Disabilities has played a major role in helping to expand understanding of health disparities associated with people with ID/DD. Three meetings held between 2009 and 2011 attended by researchers, self-advocates and policy experts became the springboard for a series of activities to promote ID surveillance (Figure 1). The term “ID” rather than “ID/DD” was used throughout these meetings, but the discussions were generalizable to ID/DD. The activities followed an action plan drafted at the second meeting and summarized in Krahn, Fox, Campbell, Ramon, & Jesien (2010). This plan included five steps, summarized below.

First (1) was to define ID in ways that are clinically, functionally, and operationally valid, as well as determining the feasibility of incorporating this definition into activities identifying people across the full range of IDs at the population level. Second (2) was to compile and synthesize a knowledge base of research, practices, policies, and procedures, including data sources and surveillance techniques that summarize our understanding of ID and the relationship of ID to health, community participation, and public health practice. Third (3) was to extend previous analyses of existing data sources to provide a more complete delineation of what is known about health status of people with ID and identify gaps for enhanced surveillance. This meant using available data that might not be population based or standardized in terms of how ID is defined, but still accounted for valid group comparisons (Lloyd M, Foley JT, Temple VA, 2014) and supplements other recent work that demonstrated disparities (Havercamp & Scott, 2014; Havercamp, Scandlin & Roth, 2004; Krahn & Fox, 2013).

Fourth (4) was to pilot state or regional demonstrations or to expand existing approaches to explore more comprehensive efforts on effective surveillance methodologies. Implicit was the need to link data from disparate sources to allow for improved understanding of the ID population.

Finally (5), the intent was to develop sustainable approaches to expand surveillance. These might include conducting a national survey or using new surveillance tools applied to existing data that could provide reliable and valid surveillance in an ongoing and systematic

manner in the U.S. The promise of using administrative data sources such as Medicaid, Special Olympics or NCI data makes this action step increasingly feasible.

Implementing the five-step plan

CDC's efforts with partners since the three meetings have begun to address needs identified in each of the steps. Examples of completed and ongoing work are described below.

A proposed definition of ID that can be operationalized for health surveillance resulted from a CDC partnership with the Association of University Centers on Disabilities (AUCD). CDC partnered with AUCD to develop *A Compendium of Health Data Sources for ID Surveillance* (CDDER, 2011). It includes a review of national data sources that hold the potential for health surveillance in the adult population with ID, including the extent to which the population with ID can be identified. Data sources were identified and systematically reviewed to develop a ranking of data sources with high, moderate, and low potential to inform U.S. surveillance of the health of the population with ID. Those data sources with a 'high' potential have adequate capture of the population with ID and could be used for surveillance if the data collection methodology was modified, if sampling were adjusted, or if the data were linked to another administrative dataset (CDDER, 2011).

CDC is partnering with the Public Health Informatics Institute (PHII) to conduct a comparison of international studies that have used administrative data to study ID prevalence and associated health issues.

Studies linking national level data sources and claims data to better understand the health and health needs of people with ID are currently underway in collaboration with the University of South Carolina.

CDC work with the Universities of South Carolina and New Hampshire is being conducted to develop algorithms to identify people with ID/DD using administrative claims data (e.g. Medicaid). CDC is now partnering with AUCD to work with five States to pilot test use of the USC algorithms for Medicaid claims data to identify people with ID/DD and to study the health of these populations. These efforts could have widespread application to improved surveillance.

CDC has also partnered with Research Triangle Institute (RTI) to identify the feasibility of developing pilot state ID/DD surveillance systems.

CDC is partnering with the University of Massachusetts Medical School's Shriver Center to conduct a systematic review of oral health interventions that reduce oral health disparity in the population with ID, with the intent to inform future clinical and policy guidance.

Findings identified through improved and expanded surveillance of people with ID can be used to inform CDC's programmatic partnerships designed to improve the health of people with ID (e.g. Special Olympics and The Arc). Likewise, the work of these organizations provides critical insight into the health needs of this population which can help inform future surveillance efforts.

Table 1 summarizes works in progress from this stepwise approach to enhancing surveillance of the population with ID in the U.S.

Summary

From the initial meeting in 2011 when 24 stakeholders grappled with the conundrum of *how* to conduct health surveillance on *what topics* for *which people* with ID to the present, substantial progress has been made in identifying the most difficult issues and working to identify potential solutions. Perhaps the greatest impact of this ongoing dialogue has been to better understand the problems so that achievable solutions are identified. Work to date has shown that no one data source effectively captures both a representative sample of the population and health data for this population, so multiple data sources need to be utilized, including administrative data and national and state survey data. Data linkages hold promise as a powerful tool to maximize the coverage of any health surveillance system designed for this population.

The standard phrasing of questions and optional responses in most existing surveys can create a barrier for accurate responses from people with ID. Potential accommodations to enable people with ID to self-respond still need to be investigated (Chang & Krosnick, 2009), including interviews split into multiple, short sessions; alternative wording or communication strategies; and additional time to respond. Mixed-mode approaches may be useful for increasing response rates for people with disabilities while controlling costs. For example, interview protocols could include face to face meeting with the person with a disability and allows for telephonic follow up with a proxy for a portion of the questions.

While self-response is always desirable and should be used as much as possible (Kaye, 2007; Stancliffe, 1999), assisted or proxy responses can facilitate the inclusion of a more representative sample of people with ID by including people that are not able to respond for themselves (Kaye, 2007).

In order to fully understand the health of people with ID, ongoing, improved surveillance is necessary. Ideally, it would include multiple approaches that identify and track children and adults across the lifespan, inclusive of both varying levels of disability and all types of living arrangements. These could include persons living with their families, independently, in community-based settings, and those living in nursing or facility-based settings, and be independent of where ID/DD services occur. This surveillance system should provide a benchmark for assessing overall shifts in the number, demographics and indicators of health of people with ID, accounting for this population's heterogeneity of conditions, experience of disability, and participation in public programs.

In the near term, expanded use of administrative data appears to offer the greatest promise for improving our understanding of the health of people with ID/DD in the U.S. in ways that may be sustainable under general principles of uniformity, simplicity, and brevity that characterize successful surveillance systems (Wharton et al, 1990). The primary advantages of moving forward is building on existing systems in ways that align with many existing resources supporting service delivery, while being able to operationally define ID/DD in

ways that many people understand. The primary disadvantages include the limited information available from these resources (e.g. health behaviors, living arrangements, severity of symptoms over different life stages, participation in or access to public programs). Working towards overcoming these remaining obstacles while expanding and refining the use of administrative data can continue to inform improvements in surveillance efforts for ID/DD. With improved surveillance, the health needs of people with ID/DD can be better identified and addressed.

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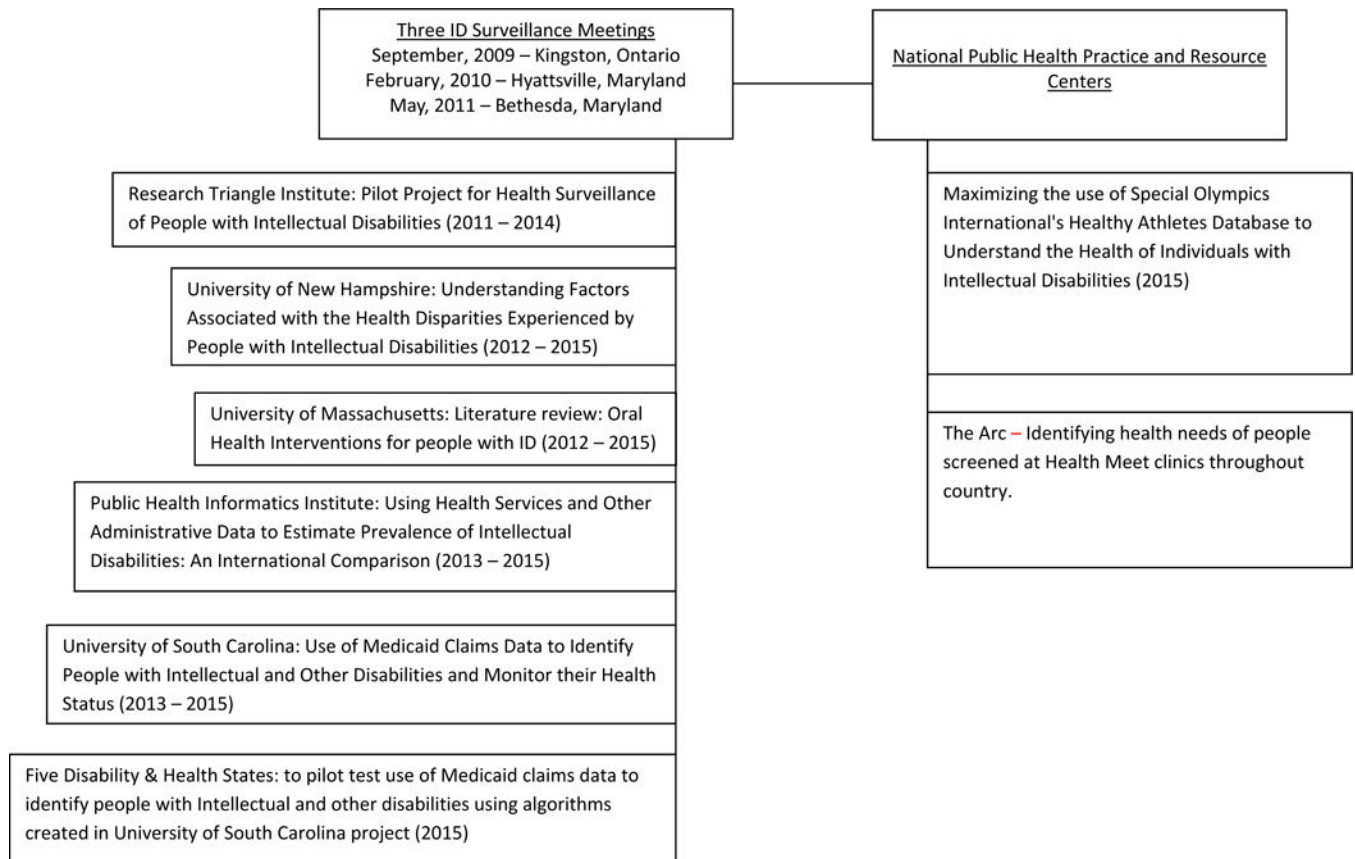


Figure 1.
CDC Activities to Expand Surveillance and Reduce Health Disparities Related to Intellectual Disabilities (ID)

Table 1

CDC Activities Associated with Efforts to Enhance Surveillance of Intellectual Disability (ID): Action Steps and Expected Products

STEPS/PLAN	Selected ACTION Steps	Expected Products
1. Define ID ("Who are we talking about?" "How do we identify them?")	Feasibility studies using different data sources	Proposed Operational Definition of ID
2. Compile and synthesize a knowledge base ("what do we know and what are the gaps?")	Systematic reviews of literature; international comparison of ID identification	Compendium of Health Data Sources Related to Intellectual Disability
3. Extend past analyses of existing data sources that capture health information for people with an ID.	Pilot study of administrative data analyses in South Carolina (USC, 2012) Pilot study of state-level data use for surveillance (RTI, 2013); Understanding Factors Associated with the Health Disparities Experienced by People with Intellectual Disabilities Using Administrative data	Analysis of Medicaid data; Systematic Review of Oral Health interventions
4. Pilot state or regional demonstrations to expand surveillance	AUCD – Pilot with 5 states (2015)	Proof of concept to determine if states can obtain and analyze Medicaid data
5. Develop sustainable approaches to expand surveillance	Build upon uses of administrative data to develop ongoing monitoring and tracking	Expanded health surveillance capacity for ID populations in the U.S.

Abbreviations:

AUCD = Association for University Centers

USC – University of South Carolina

RTI – Research Triangle Institute, Inc.